



Indiana State Department of Health

Overview of Cystic Fibrosis Newborn Screening for Parents

What is newborn screening for cystic fibrosis?

Before babies go home from the nursery, they have a small amount of blood taken from their heel to test for a group of conditions. One of these conditions is **cystic fibrosis**. Babies who screen positive for cystic fibrosis need a second test done to confirm they have cystic fibrosis. **Not all babies with a positive newborn screen will have cystic fibrosis.**

What is cystic fibrosis?

Cystic fibrosis, or CF, affects breathing and digestion of food. Babies with CF may have difficulty gaining weight. They also have thick mucus in their lungs. This thick mucus is more difficult to cough up. People with CF also have extra salt in their sweat.

What causes CF?

CF is a genetic condition. Everyone inherits two copies of the CF gene, one from their father and one from their mother. People with one abnormal CF gene are healthy. People with 2 CF gene changes have cystic fibrosis.

What are the symptoms of CF?

Every child with CF is different. Some babies will have very few symptoms until they are older. Common symptoms include:

- Difficulty gaining weight
- Thick, greasy stools
- Coughing
- Wheezing

What is the treatment for CF?

There is no cure for CF. However, there are treatments that can help with the symptoms. With early diagnosis and treatment, most children with cystic fibrosis can grow up and live into adulthood.

Although there is no cure for CF, good medical care makes a difference. Children with CF should see a doctor who specializes in cystic fibrosis, as well as their regular pediatrician.

Where are the CF centers in Indiana?

The locations of CF centers in Indiana can be obtained by calling the Newborn Screening Program CF Coordinator at the Indiana State Department of Health at (888) 815-0006.

Where can I get more information about cystic fibrosis?

- **Cystic Fibrosis Foundation**
 - www.cff.org
 - Toll-free (800) 344-4823
- **Indiana State Dept. of Health**
 - Toll-free (888) 815-0006
- **About Special Kids (ASK)**
 - www.aboutspecialkids.org
 - Toll-free (800) 964-4746